

*Texas  
Office For  
Prevention of  
Developmental  
Disabilities*

2013

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*REPORT TO THE 83<sup>rd</sup> TEXAS LEGISLATURE*



Texas Office for Prevention  
of Developmental Disabilities

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Minding the Minds of Children





February 1, 2013

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The Honorable Rick Perry  
Governor of Texas

The Honorable David Dewhurst  
Lieutenant Governor

The Honorable Joe Straus  
Speaker of the Texas House of Representatives

The Honorable Members  
Texas Legislature

Dear Distinguished Colleagues:

Pursuant to Human Resources Code Chapter 112, Subchapter C, Section 112.051, it is my privilege to submit this report to the Legislature on behalf of the Executive Committee of the Texas Office for Prevention of Developmental Disabilities (TOPDD). We are proud of the achievements of this unique agency and its essential work in promoting disability prevention activities in Texas, and we look forward to greater accomplishments in years to come.

This report was designed to provide information about the unique work of TOPDD, the latest research in disabilities prevention, and the role of prevention in achieving cost savings. We hope that you find the information helpful, and look forward to answering any questions you might have.

Sincerely yours,

Richard Garnett, Ph.D.  
Chair, TOPDD Executive Committee



## **TABLE OF CONTENTS**

<b>INTRODUCTION.....</b>	<b>1</b>
<b>ABOUT TOPDD.....</b>	<b>3</b>
<b>FACTS &amp; FIGURES.....</b>	<b>4</b>
<b>TOPDD’s INITIATIVES.....</b>	<b>7</b>
<b>RECOMMENDATIONS.....</b>	<b>12</b>
<b>CONCLUDING REMARKS.....</b>	<b>16</b>
<b>APPENDICES.....</b>	<b>17</b>
<b>APPENDIX A.....</b>	<b>17</b>
<b>APPENDIX B.....</b>	<b>20</b>
<b>APPENDIX C.....</b>	<b>22</b>
<b>REFERENCES.....</b>	<b>24</b>

## INTRODUCTION

Prevention of developmental disabilities assures a better quality-of-life for individuals, and decreases the economic impact on Texas from service provisions.

During the past 30 years, significant advances in research allowed for the prevention of many cases of intellectual and developmental disabilities.

For example, every year our nation prevents:

- **250 cases** of intellectual disability due to phenylketonuria (PKU) by newborn screening and dietary treatment;
- **1,000 cases** of intellectual disability due to congenital hypothyroidism thanks to newborn screening and thyroid hormone replacement therapy;
- **1,000 cases** of intellectual disability by use of anti-Rh immune globulin to prevent Rh disease and severe jaundice in newborn infants;
- **5,000 cases** of intellectual disability caused by Hib diseases by using the Hib vaccine;
- **4,000 cases** of intellectual disability due to measles encephalitis thanks to the measles vaccine; and
- **Untold numbers of cases** of intellectual disability caused by German measles during pregnancy thanks to rubella vaccine (Alexander, 2008).

However, not all developmental disabilities are preventable and as an agency, The Texas Office for Prevention of Developmental Disabilities (TOPDD) focuses on the preventable developmental disabilities caused by prenatal alcohol exposure and childhood brain injuries. Many interventions preventing child brain injury and prenatal alcohol exposure have reduced the prevalence of intellectual and developmental disabilities. Preventive interventions such as child safety seats and bicycle helmets reduce head trauma; removing lead from the environment reduces brain damage in children. Early intervention programs with high-risk infants and toddlers have shown positive impacts on intellectual functioning and a reduction of the likelihood of secondary disabilities. Early comprehensive prenatal care and preventive measures prior to and during pregnancy increase a woman's chances of having a healthy child. TOPDD builds on these accomplishments to move Texas to the forefront of the prevention of developmental disabilities.

***Role:*** As the convener on preventable developmental disabilities, TOPDD brings policy and clinical issues forward to engage community and state-level partners to prevent developmental disabilities at the state, regional, and community level. Using evidence-based practices as its foundation, TOPDD educates the community and professionals, organizes intervention services, and develops policies to improve services. TOPDD adheres to evidence-based research and practices to ensure that the work it does has a palpable and positive impact on communities throughout Texas, making research relevant to the practical needs of people.

***Public Health priority around Disability Prevention:*** Recognizing that the state of one's health is a complex intersection of various factors, TOPDD's prevention works are designed to address multiple systems in order to influence people's health behaviors. TOPDD also focuses both on preventing

disabilities before they occur, as well as implementing interventions that lessen and sometimes eliminate the impact of disabilities. By both preventing disabilities before they occur and intervening when they do, TOPDD reduces the economic losses caused by preventable conditions. When one considers the implications of preventing a disability and allowing thousands of individuals to realize their full potential, the ripple effect on the individual, family, community, and state cannot be overstated.

## ABOUT TOPDD

**Mission:** TOPDD works to prevent the economic and human costs associated with preventable developmental disabilities in order to improve the public health of Texans.

**Structure:** TOPDD is an independent state agency overseen by an executive committee with members appointed by the Governor, Lieutenant Governor, and Speaker of the House. Executive Committee members are policy makers and experts on developmental disabilities and prevention, which well-positions TOPDD to improve and develop statewide prevention strategies.

**Minding the Minds of the Children of Texas:** Human development across the life-course is most impacted by issues affecting the brain. “Minding the Minds of Children” reminds everyone involved with TOPDD that the prevention actions of the office are intended to keep the minds of children healthy and ready to develop fully. Implementing strategies that reflect the values of “Minding the minds of children” will change the future of the state and better the lives of Texans.

### *TOPDD’s Executive Committee*

TOPDD is governed by an Executive Committee. The Executive Committee is chaired by Richard Garnett, Ph.D., and Marian Sokol, Ph.D., is the vice chair of the committee.

### ***Executive Committee Members***

#### **Appointed by the Governor**

Ashley Givens (Dallas)  
Director of Special Events,  
Texas Scottish Rite Hospital for Children

Valerie Kiper, RN, MSN, NE-BC (Amarillo)  
Quality Consultant, Eastern Region  
Universal Health Services, Inc.

Marian Sokol, Ph.D., MPH (San Antonio)  
Vice Chair of TOPDD  
Director of External Affairs & Development

#### **Appointed by Lt. Governor**

Angelo P. Giardino, M.D., Ph.D. (Houston)  
Medical Director, Texas Children’s Health Plan

Joan Roberts-Scott (Austin)  
Directorate Manager,  
Texas Department of Assistive and Rehabilitative Services

Mary S. Tijerina, Ph.D., LMSW-AP (San Marcos)  
Associate Professor, Texas State University

#### **Appointed by the Speaker of the House**

Richard Garnett, Ph.D. (Forth Worth)  
Psychology Professor, Texas Christian University  
Member of Texas Silver Haired Legislature

## FACTS AND FIGURES

### Brain Injury

Prevalence of Brain Injuries in Texas (Texas Traumatic Brain Injury Advisory Council Report, 2007):

- Approximately **144,000 individuals** sustain a brain injury each year.
- Of those individuals, **5,700** will have a permanent disability.
- Amongst children and youth, **3,500 children** 0-19 suffer a brain injury, with **a third** getting lifelong/long-term disability.
- In 2007, **479,000 Texans** lived with some sort of brain injury related disability.
- Up to **95% of brain injuries** in Texas may be preventable.

The cost of treating an individual with a brain injury is estimated to be:

- Around **\$4 million** throughout a **lifetime**.
- Hospitalization cost rise up to about **\$268 million each** year for children with a brain injury
- Texas pays about **\$1 billion each year** to cover the comprehensive needs of people with a disability stemming from a brain injury.

In children, brain injury occurs most often as a result of falls. Motor vehicle accidents and being struck by or against events, as well as physical abuse (“assaults,”) are also common causes. According to the Center for Disease Control and Prevention, approximately 18% of all brain injury related emergency department visits involved children aged 0 – 4 years.

Severe brain injury is reported to be the leading cause of disability in young people in the U.S., but the evidence is limited. Most studies of the outcomes of brain injuries in children and youth are based on case series from selected hospitals or rehabilitation facilities, small regional samples, or anecdotal reports. Few studies have followed the same group of children over time to properly document the lifelong effects of a brain injury. With a brain injury, an individual’s personality, mental health, behavior, and cognitive/intellectual abilities change.

The impact of a brain injury on an individual has widespread implications, far beyond just medical and familial lines. Individuals with brain injuries often face difficulty in daily life.

- Only **5%** of people with a brain injury receive the rehabilitation services that they need to reach their “maximum potential for recovery”.
- Five years after a brain injury, **31% of adults** are in trouble with the law.
- Five years after a brain injury, **33% of youth** are in trouble with the law.
- There appears to be a gap between diagnostic assessment of brain injury and appropriate services for children who have experienced one. For example, there are many children in Texas schools who have a brain injury, even though there are relatively few (**1,350 Texas students according to TEA**) who are receiving special education services for a brain injury.

Statistics for brain injuries are limited to those who come in contact with one of the reporting systems; it does not include data for those who did not seek medical treatment, or who fall through one of the cracks in the reporting system.

## FASD

Research on Females and Drinking:

The CDC recently released an alarming study that indicated that women, especially those of child-bearing age, are catching up to men in alcohol use (Center for Disease Control Female Binge Drinking, 2013):

- **1 in 5 high school girls** binge drink (four or more drinks in one sitting)
- **1 in 8 adult women** binge drink. Binge drinking is the most dangerous kind of drinking for the fetus and women who binge drink also tend to be frequent drinkers.
- According to the Behavioral Risk Factor Surveillance System (BRFSS, 2011), **43.8% of women age 18-44 in Texas drink**, with **11.4% engaged in binge drinking**. The Pregnant Risk Assessment and Monitoring (PRAMS, 2011) report reinforced this information with **44.3% of women reported drinking three months before they were pregnant**.

Dr. Ira Chasnoff (world renowned expert on FASD) implemented a screening and brief intervention program in Texas through the state's "Healthy Start" sites in San Antonio and Rio Grande Valley. The screening identifies women using alcohol and other drugs while pregnant. Women who score positive are given a brief intervention (*I am Concerned*).

- Over **31.4% screened positive screen** for substances that can alter the structure and function of a developing brain.
- **19.4% were using alcohol**
- **50% of the women** with a **positive screen** were using **more than one drug, with alcohol use** occurring in **90% of these pregnancies**.

Today, the number of children exhibiting serious behavior challenges at a very young age is increasing, along with the diagnoses of mental illness. FASD is linked to several of those diagnoses. While most people are aware that ADHD can be genetic, it can also be caused by prenatal alcohol exposure.

Dr. Ann Streissguth from the University of Washington conducted a longitudinal study on people with Fetal Alcohol Syndrome (FAS), and the following were the outcomes and prevalence numbers (1996).

- **94% of the individuals** from the study have a mental illness as well as FAS.
- **60% of the individuals** from the study have been charged with or convicted of a crime. (Personal crimes like child molestation, theft, and murder were the most common.)
- The majority of the individuals from the study do not reside in a traditional home environment: **40% of the individuals** are incarcerated, **30%** are in a mental health program, and **20%** are in a residential chemical dependency and recovery program.

The following data related to children who are in the child welfare system:

- **70%** of children in foster care have an FASD (NOFAS, 2013)
- **80%** of children with an FASD are not raised by birth-parents; many of them end up in the system.

Additionally, many of the children impacted by alcohol are born with a low birth-weight and may have life-long medical problems.

The following is an analysis of costs that people with developmental disabilities may experience. According to research from Open Minds (including the chart below,) the vast majority of these costs are ultimately sourced from public funds. It is easy to understand why most people who are impacted by either FASD or a brain injury may experience financial difficulties.

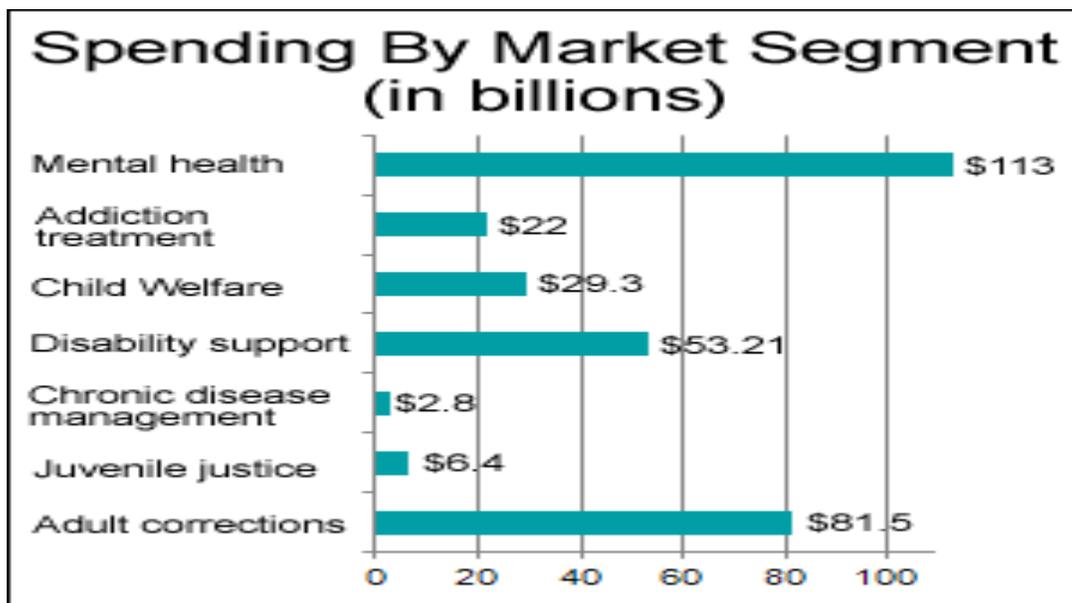


Figure from Open Minds Management Newsletter (2013)

These human and financial costs are important for the state of Texas to analyze further. Each new case of Fetal Alcohol Syndrome (FAS: a condition under the FASD umbrella) costs between \$1-3 million per individual annually. As mentioned earlier, the cost for a brain injury has been estimated to be \$4 million per person. These figures average the cost from a wide array of services the state may have to render because a person has FASD.

**Fewer Texans with preventable developmental disabilities means significant cost savings to the state.**

## TOPDD's INITIATIVES

Much of TOPDD's projects this biennium have been around statewide planning on FASD. Texas is a national leader as one of the few states with a comprehensive, collaborative plan on FASD. This plan is the agency's guiding force for all of its work. TOPDD received a grant from the Meadows Foundation to implement the plan and is actively addressing its goals. The following accomplishments are a small snapshot of the overall work the office does to prevent developmental disabilities.

### Accomplishment 1

*Convened over 50 organizations to develop the state's first plan on FASD*

- The plan involves the full spectrum of human service systems, both public and private, and infuses prevention throughout these systems.
- Identified priority areas and organized standing, active committees to lead the charge on implementation.
- Has initiated the first FASD Training Institute, which will train professionals from throughout Texas on the basics of identification, prevention, and intervention
- Is developing "Communities of Excellence" programs in Houston and San Antonio to launch pilot programs that will bring the FASD planning work to the community level

Goals of FASD plan include:

- 1) Professional Education and Community Awareness
- 2) Screening and brief intervention to prevent FASD
- 3) Using existing services that reach high risk populations (such as women in treatment & recovery programs)
- 4) Access to services for children with an FASD

Total attendance for the planning program is 320. However, the diversity of the organizations and individuals involved demonstrates the commitment of Texans to this issue. Organizations such as court representatives (judges, attorneys, etc.), medical providers (pediatricians, nurses, community health workers), children's advocacy organizations, treatment and recovery agencies, state agencies such as Early Childhood Intervention (ECI), Children Protective Services (CPS), and Department of State Health Services (DSHS), and consumers (family members affected by FASD) actively participated to move this project forward. Together, representatives of these groups developed priorities for the state and are crafting solutions on a state and regional level. Among the work being done are: changes to public policy, implementing new initiative's within their organizations, and developing across system and agency initiatives.

### Accomplishment 2

*Organized a statewide awards program for child safety activists, bringing together safety leaders from throughout the state to celebrate this work and the people they serve.*

J.C. Montgomery, Jr. Child Safety Award Ceremony

To identify and celebrate best practices in child safety, TOPDD established an award that highlights the achievements of a few stand-out individuals doing tremendous work in the area. The award is far more than a single event. TOPDD used the awards as a platform to create a best practice to build interest and involvement around child safety.

The award is named after J.C. Montgomery because his impactful role as a leader in safety. J.C. Montgomery is the Chairman at Texas Scottish Rite Hospital for Children in Dallas, a first-class facility serving patient families at no charge. From 1994-2009, he also served as member of TOPDD's executive committee in various capacities, including chairman. As a member of the executive committee, he was instrumental in increasing awareness about the importance of child safety education.

To receive the award, an organization or individual had to be nominated and then go through a competitive application process. The Child Safety and Injury Prevention Committee of TOPDD sought nominations and selected four recipients of the award based on the following criteria:

- Innovation, creativity
- Programs and activities that can be replicated and individuals or groups that would like to share their knowledge or experience with others
- Grassroots involvement that engages the youth themselves in the effort
- Demonstration of a strong collaborative spirit in the community
- Involvement of groups not typically associated with child safety
- Efforts that can demonstrate measurable success; metrics that go beyond the number of people participating
- Active leadership or involvement by individuals who may be marginalized in some way (people with disabilities, minority groups, economically disadvantaged)
- Organizations or individuals that can demonstrate the ability to overcome barriers or challenges to the work

The following individuals and organizations were chosen based on the initial criteria, and now serve as strong allies in TOPDD's quest to prevent brain injuries amongst children.

Rosie Valadez-McStay: As the Director of Government and Community Relations at Texas Children's Hospital in Houston, TX, she has led the Center for Childhood Injury Prevention for over a decade. She is a dedicated and mission-oriented leader that truly aids in the success of the Center for Childhood Injury Prevention. Among the numerous and diverse programs Rosie Valadez-McStay organizes at Texas children's Hospital are Safe Kids Greater Houston and Kohl's Safe at Home Infant Sleep Awareness Initiative. She also organizes several ongoing activities such as inspecting child car seats, providing free bike helmets to low-income children, and providing safety education in areas such as bicycling, swimming, and pedestrian safety.

Cindy Healy: She is a physical education teacher at Gattis Elementary School in Round Rock, TX, where she rallies the school, community volunteers, donors, and bicycle helmet sponsors to organize a safety event that is fun and informative for all. Part of her mission is to go the extra-mile to ensure everyone has the opportunity to participate, and make sure children with disabilities have

accommodating provisions. Cindy Healy is the inspiration that mobilizes her school and community to champion the importance of child safety.

Frisco Fire Department: The organization received the award because of their safety education program, Frisco Fire Safety Town, which is fun, innovative, and highly interactive. While the program begins in a standard classroom, the interactive component of the program introduces children to a fire engine and safety house where they learn about household hazards, fire, and severe weather. Lastly, the educational program takes the children to a faux street with the usual markings of a real-world street. Children learn during the faux street portion the importance of seat belts, bicycle helmets, and pedestrian crossing. Since January 2007, the year-round program has had more than 170,000 visitors learn safety strategies. Chief Mark Borchardt accepted the award on behalf of Frisco Fire Department.

The Texas Medical Association: The organization received the award because of their program Hard Hats for Little Heads Program, which recognizes that proper helmet use can reduce up to 85% of head injuries. Physicians, medical students, and community members partner together under the program to urge children and adults to use a helmet in all wheeled sports. Free helmets are provided to children, along with education on how to properly fit the helmet. Since physicians host the safety events, families receive the child safety message from a trusted source, which makes the program even more special. Thanks to Hard Hats for Little Heads, more than 100,000 children were given new bicycle helmets. Dr. Bruce Malone, president of the Texas Medical Association, accepted the award on behalf of the organization.

### **Accomplishment 3**

*Trained over 2,500 professionals who reach thousands of women and families*

The following organizations are a glimpse of the professionals TOPDD has trained on FASD.

- The National Association of Social Workers
- Department of Family Protective Services (DFPS) Partners in Prevention
- Prevent Child Abuse Texas
- Healthy Youth Partnership
- Texas Foster Families Association
- Methodist Healthcare Ministries, Wesley Nurse Program
- Early Head Start Austin
- Promotoras Community Health Workers (DSHS conference)
- Texans Care for Children Behavioral Health conference

### **Accomplishment 4**

*Conducted research on education for children with developmental disabilities*

Educational Survey on Transitions for Children with Developmental Disabilities

TOPDD and The Texas Council for Developmental Disabilities worked together to develop a collaborative report on Developmental Disabilities.

Based on discussions with family members of and service providers for people with developmental disabilities, it appeared to TOPDD that there were issues related to access and quality of services that would not be captured in reviewing standard data from state agencies and other entities. To better understand these issues, TOPDD conducted 2 surveys, one for family members/consumers and one for professionals/service providers.

TOPDD developed a white paper based on the results. Below is an executive summary of the white paper.

**Access to services was a major issue identified from the survey.**

- 80% doubted the effectiveness of the eligibility process
- 70% thought that the schools were not following the guidelines
- 90% thought parents did not understand their rights

Many survey participants described what they considered “delay tactics” in the eligibility process that pushed entrance into the special education programs off for an additional year. Others said that even when children were found eligible, that their educational plans were never fully implemented. Barriers to obtaining special education services were a major concern of the families and service providers.

**83.6% of key informants (service providers) thought that educators knew “nothing, a little bit or were somewhat knowledgeable of developmental disabilities”.** Since only special education teachers are required to take coursework on developmental disabilities, the majority of educators would know little about developmental disabilities. Also, to address teacher shortages, many teachers use alternative teacher certification programs which have very limited course requirements.

**90% of consumers believed that standardized testing was hindering children with developmental disabilities.** Standardized testing (such as the STAR test) is being used as the single most important metric in evaluating schools. The emphasis on these test results seems to result in less emphasis on educating children with disabilities. Results from the survey also found that vocational programs were nearly non-existent, and participants felt they are especially important for children with developmental disabilities.

A unique set of circumstances has created unusual and unintended challenges for people with developmental disabilities. When people consider that one in six children has a developmental disability and that 1) the current system to evaluate schools has no metric related to children with developmental disabilities, 2) most teachers receive no training in working with such a significant portion of the student body, and that 3) schools are being required to make drastic cuts in budgets, which may be leading some schools to push past the limits of eligibility law in an effort to save funds.

Often well intended goals have unexpected outcomes.

- Onerous requirements for teachers are not desirable. However, children with developmental disabilities are integrated in regular education and form a big part of the student body. It places

the student and teacher at a disadvantage when educators do not receive the education they need to serve children with developmental disabilities.

- Objective metrics and accountability is an important goal for schools, but the standardized tests were designed for typical children. With finances tied to test outcomes, increased focus would be on meeting the needs of typical children in order to assure future funding.
- Costs reductions may have been needed to balance budgets, but it may have led schools to take drastic measures to limit those who receive special education.
- There has been an emphasis on students' preparation for college, which is extremely important for many students. However, all children, including those with developmental disabilities, are not college bound. Preparation for the world of work is especially critical for children with developmental disabilities.

While the goals of many of these decisions were worthwhile, if the decision-making process does not include a close examination of how the decision will impact children with disabilities, their needs will not be met. If we are serious about building an educated population and a strong workforce for the future, we need to carefully consider the needs of people with developmental disabilities and be intentional about how decisions impact all children in Texas.

## RECOMMENDATIONS

- 1) Require education about preventing developmental disabilities for all degree programs for pediatricians, social workers, licensed professional counselors and teachers as well as relevant certificate programs (certified alcohol and drug abuse counselor) and require that certification, licensure, and other testing included related questions.
  - It is crucial that we eliminate the “a little alcohol during a pregnancy is okay” message that so many women receive from their physician and from the community.
  - FASD is the biggest cause of intellectual disabilities, yet even special education teachers may not obtain any information on it during their collegiate years. The same is true on the impact of brain injuries; teachers are not trained to engage students with those conditions, yet they have children in their class who have them. The complete lack of knowledge about these issues crosses many disciplines.
  - Children are being misdiagnosed and mistreated because of the lack of education about the root cause and therefore the appropriate treatment for the disabilities. This is costly mistake because an inaccurate diagnosis can lead to ineffective treatment.
- 2) Texas needs to conduct universal screening and brief interventions for women related to the risk factors around developmental disabilities (substance use, mental illness, etc). Furthermore, there should be screening of all children ages birth to 8 years old to identify and address any medical, behavioral, developmental, or learning issues as early as possible so that families can obtain needed supports.
  - Validated, effective screening tools are available which screen for alcohol and other drug use, mental health needs, and domestic violence. Identifying who is at risk is the first step to eliminating the problems.
  - The evidence on the effectiveness of brief interventions is overwhelming. It is absolutely clear that screening and brief interventions can and do prevent prenatal alcohol exposure.
  - Evidence-based home-visiting programs can promote optimal growth and brain development in young children by enhancing parenting, family functioning, and financial self-sufficiency amongst parents with at-risk behavior.
- 3) Representative Dawnna Dukes submitted House Bill 446 relating to information about Fetal Alcohol Syndrome be provided to pregnant patients. HB 446 mandates that a health care provider that cares for a pregnant woman must: 1) Counsel the woman about the risks of drinking alcohol while pregnant on the first visit; 2) Provide a pamphlet with the risks of drinking while pregnant, including information about Fetal Alcohol Syndrome; 3) Document on the patient’s record that the information was provided to the pregnant woman, and have the pregnant woman sign an acknowledgement that such care was provided to her; 4) Retain the documentation on the provider’s records for five years.

- TOPDD recommends the passage of HB 446 in order for healthcare providers to counsel women about the risks of drinking alcohol while pregnant.
- 4) Recognize and address the relevance of health disparities as it relates to prevention, developmental disabilities, and specifically FASD and brain injuries. There are a host of issues related to health disparities that need to be addressed.
- Health disparities cuts across all areas from toxicology screenings, to receiving interventions for disabilities, to over-representations of people of color and those who do not have financial resources in the juvenile justice and criminal justice systems (Chasnoff, 1990). This has life-long implications.
  - Medical care (especially prenatal care and well woman visits, mental health services, intervention services such as occupational therapy, speech therapy, etc.) are far less accessible to disadvantaged people. Additionally, there are many financial barriers related to safety. The costs associated with helmets, equipment maintenance, home safety devices, etc. are simply out of reach for many disadvantaged people.
  - Have trainings that incorporate cultural sensitivity throughout their design to support care and reduce disparities for all individuals.
- 5) Address the root causes of child abuse, neglect, childhood injury-mental illness, and substance abuse.
- It is very unusual that a parent would willfully put a child at risk for a head injury or set out to abuse or neglect their children. Children at greatest risk are the children whose parents have a behavioral health disorder.
  - Behavioral health and social service agencies need guidance about how to develop their infrastructure to respond to any and all new opportunities that arise from the new health care policies to expand their services. A concerted effort by the state to build the capacity of these agencies will allow them to expand their services. Alternately, if our current funding structure is eliminated and the agencies are not prepared for the changes, the implications could be devastating.
- 6) To better understand the context behind FASD and brain injuries to children, increased investments in data collection is needed to strengthen prevention strategies.
- Data-tracking system should be implemented to showcase the connection between developmental disabilities and brain injuries. More importantly, this type of system can illuminate the kinds of behaviors that increase the risk of children getting a brain injury.
  - Prevalence studies are needed to assess alcohol exposure during pregnancy and document how many Texas babies are born with an FASD.

- 7) Greater public and professional awareness of child safety injury prevention is needed in order to highlight the best-practices that exist to prevent debilitating head injuries.
- Develop and distribute information about brain injuries, resources related to brain injuries, and prevention of brain injury programs to the general public to increase awareness.
  - Invest further resources in developing best-practices preventing head injuries to make available to all the organizations and individuals working to combat head injuries.
  - Provide the most up-to-date information on brain injuries and child safety through websites easily accessible to individuals coping with a brain injury. This means dissemination of vital research and practices about brain injuries to the public.
- 8) Expand efforts to reduce sports injuries.
- Recent research on the lifelong impact of concussions needs to result in policy change in sports through clubs and schools. Very young children are playing competitive sports and need to do so safely.
  - The use of helmets is an important tool in safety-cyclists, skate boarders, etc. Vendors of sports equipment should provide information about the importance of wearing a helmet and how to wear a helmet.
- 9) Continue state investment in evidence-based home visitation programming.
- Evidence-based home visiting programs serve to enhance parenting, family functioning, and financial self-sufficiency, and promote optimal growth and brain development in young children.
  - These programs have produced measurable results and can help to mitigate risks, significantly improving a child's chances of growing up healthy and prepared to succeed.
- 10) Health care for women is an important factor in preventing developmental disabilities.
- Efforts to encourage women to obtain care and efforts to increase access to the full array of health care services are important prevention tools.
  - Well woman visits, preconception care, prenatal care, behavioral health services bolster women's health and if women are healthier, their children will be healthier too.
- 11) Community based housing and support services for people with developmental disabilities must be a priority for Texas.

- As described earlier in this report, both people who have had a brain injury and those who have an FASD have a high incarceration rate. This is unacceptable and costly.
- Often intelligence quotients alone are used to determine eligibility for services. Often people with an FASD have a normal IQ but typically have such significant gaps in their ability to process and act on information that they cannot live independently. We need more flexible guidelines that look at the whole person to determine eligibility.
- Rebalance the system that serves people with a developmental disability by expanding cost-effective policies that honor the choices of individuals to live in the most integrated setting to meet their needs, identifying and providing supports and services to meet the needs of persons when and where they need them, and transferring the inevitable savings so that more persons with disabilities have the opportunity to be included in their communities.

**TOPDD supports the following exceptional item requests that can positively impact children:**

- Fund Early Childhood Intervention (ECI) Forecasted Caseload and Maintain Service Levels for Eligible Children (DARS Exceptional Item Request).
- Maintain caseloads for home and community-based services (DADS Exceptional Item Request).
- TWC Foster Day Car Services (DFPS Exceptional Item Request).
- Support the Acquired Brain Injury office (HHSC Exceptional Item Request).
- Increase behavioral health treatment options (DSHS Exceptional Item Request).
- To meet the increasing need around developmental disabilities, TOPDD endorses its own exceptional item request (HHSC Exceptional Item Request).

## **CONCLUDING REMARKS**

The research is clear about how to prevent developmental disabilities, especially FASDs and brain injuries in children. As described in the introduction of this report, nationally, there have been tremendously successful efforts in reducing/eliminating developmental disabilities caused by PKU, Rh disease, rubella, HiB, etc. The research on FASD is fairly new and presents new opportunities for prevention. Child safety is an area that is constantly evolving. There are new inventions every day which lead to new safety hazards. However, tremendous strides have been made in this area. Today, seatbelts are a part of everyday life. Now with the use of cell phones and texting, we have new challenges. However, public policy has always been a component of all of the most successful public health efforts. TOPDD is pleased to submit this report and hope that it provides some useful information in your decision making process. We also would be happy to provide more information about how the esteemed members of the Texas Legislature can lead the way in our goal to “mind the minds of children of Texas”.

## APPENDICES

### *Appendix A*

#### Important Definitions

***Developmental Disabilities:*** TOPDD conforms to the federal definition which states that a developmental disability is a severe, chronic disability of an individual five years of age or older. Furthermore, the disability is attributable to a mental or physical impairment or combination of mental and physical impairments, manifests before the individual becomes 22 years old, and the disability is likely to continue indefinitely. Lastly, the disability results in substantial functional limitations in three or more of the following areas of major life activity:

- Self-Care
- Receptive and expressive language
- Learning
- Mobility
- Self-Direction
- Capacity for independent living
- Economic self-sufficiency

The definition reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age five, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

***What are some causes of preventable developmental disabilities?*** There are many causes of preventable developmental disabilities. Everything from nutrition (such as mercury in the diet), to environmental toxins (such as lead in paint), and even child maltreatment can negatively impact the development of child's brain and cause disabilities. Fetal Alcohol Spectrum Disorders (FASDs) and Brain Injuries related to child safety are among the most prevalent causes of preventable disabilities. What is most tragic about FASDs and Brain Injuries, in addition to their prevalence and the extent of the losses, is the breadth of the losses. Many areas of the brain can be impacted and they are involved with everything from sensory perception to emotional regulation, mental health, as well cognitive skills. Since these areas are typically collectively compromised, the combinations of disabilities that result are incredibly challenging.

***Evidence-based practices:*** While the term "evidence-based practices" is commonly used, the term is often misunderstood. The following are the characteristics of evidence-based practices:

- Decisions are driven by the best available scientific evidence.
- Business approaches and strategic planning is the framework for the work so that a systematic approach is used-instead of arbitrarily selecting targets and goals.

- All critical parties actively participate in the decision making process, so that plans can actually be implemented.
- Sound evaluations are an integral component of the effort-to facilitate continuous quality improvement.
- Dissemination of knowledge on an ongoing basis is embedded in the program-to build the body of information on what works. (Brownson, 2009).

***Fetal Alcohol Spectrum Disorders (FASD):*** An umbrella term used to describe the range of neurological, behavioral, and physical conditions caused by the use of alcohol during a pregnancy; it refers to specific conditions such as:

Fetal Alcohol Syndrome (FAS)  
 Partial Fetal Alcohol Syndrome (PFAS)  
 Alcohol-Related Neurodevelopmental Disorder (ARND)  
 Alcohol-Related Birth Defects (ARBD)

FASD is a brain-based physical disability that effects an individual’s physical, behavioral, and learning capabilities. Often, a person with an FASD has a mix of these problems.

***Possible physical effects are:***

Brain Damage

- Facial Anomalies
- Growth Deficiencies
- Defects of the heart, kidneys, and liver
- Vision and hearing problems
- Skeletal defects
- Dental abnormalities

***Key signs of brain damage:***

- Difficulty with assessment, judgment, impulse control and reasoning
- Misunderstanding of cause and effect
- Inability to generalize or think abstractly
- Trouble focusing and hyperactivity, poor money, emotional immaturity and social skill deficits and learning disabilities.

***Brain Injury:***

A brain injury is caused by a bump, blow, jolt to the head, or a penetrating head injury that disrupts the normal function of the brain. Not all blows or jolts to the head result in a brain injury. The severity of a brain injury may range from “mild,” i.e., a brief change in mental status or consciousness, to “severe,” i.e., an extended period of unconsciousness or amnesia after the injury. The majority of brain injuries that occur each year are concussions or other forms of mild brain injury.

The brain injuries that lead to developmental disabilities are considered “severe”, and result in a lifelong challenge that stem from the initial severe brain injury. There are two types of severe brain injury, each with an associated cause.

***Closed Brain Injury*** – An injury to the brain caused by movement of the brain within the skull. Causes may include falls, motor vehicle crash, or being struck by or with an object.

***Penetrating Brain Injury*** – An injury to the brain caused by a foreign object entering the skull. Causes may include firearm injuries or being struck with a sharp object.

A severe brain injury may lead to a wide range of short- and/or long-term issues affecting:

- *Cognitive Function* (i.e. attention and memory)
- *Motor function* (i.e. extremity weakness, impaired coordinator and balance)
- *Sensation* (i.e. hearing, vision, impaired perception and touch)
- *Emotion* (i.e. depression, anxiety, aggression, impulse control, personality changes)

A non-fatal severe brain injury may result in an extended period of unconsciousness (coma) or amnesia after the injury. For individuals hospitalized after a brain injury, almost half (43%) have a related disability one year after the injury (reference on cdc). Brain injuries can also cause epilepsy and increase the risk for conditions such as Alzheimer’s disease, Parkinson’s disease, and other brain disorders that become more prevalent with age (TBIAC, 2007).

## Appendix B

### WHAT IS FASD?

FASD (Fetal Alcohol Spectrum Disorder) is an umbrella term used to describe the range of neurological, behavioral, and physical effects caused by the use of alcohol during a pregnancy. It refers to specific conditions such as:

- Fetal Alcohol Syndrome (FAS)
- Partial Fetal Alcohol Syndrome (PFAS)
- Alcohol-Related Neurodevelopmental Disorder (ARND)
- Alcohol-Related Birth Defects (ARBD)

**FASD is a brain-based physical disability.** As such, FASD is permanent, life-long and cannot be cured.

### WHAT DOES FASD LOOK LIKE?

Most children with an FASD may look completely normal. **You can't physically see brain damage-** you can only see the results in the behavior of the individual. The key characteristics of FASD brain damage are:

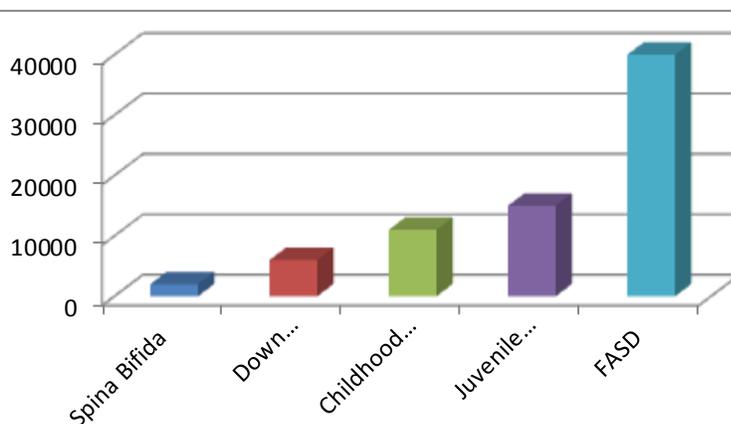
- **Difficulty with assessment, judgment, impulse control and reasoning** which often lands them in trouble at home, at school, and with the law (They may be able to recite the rules, but they are unable to use them to govern their behavior);
- **Misunderstanding of cause and effect** which often leads to high rates of recidivism in the criminal system and problems with discipline because they are unable to predict the consequences of their actions;
- **Inability to generalize or think abstractly** means that they are unable to apply lessons learned in one situation to another (They may understand that they're not to run into the street in front of their house, but may can't apply that lesson instinctively to other streets);
- **Trouble focusing and hyperactivity, poor memory, emotional immaturity and social skill deficits, and learning disabilities** often mean that they perform poorly in school, have trouble holding jobs, and difficult to manage at home.

***FASD is a birth defect that is 100% preventable. If no woman consumed any alcohol during her entire pregnancy, no child would be born with an FASD.***

### HOW PREVALENT IS FASD?

Experts estimate that **an FASD occurs in 1 in 100 live births** (1% of all births). Thus, of the 4 million infants born each year, **40,000 will be born with an FASD.**<sup>i</sup> For comparison, 2 in 1,000 children are born with Juvenile Diabetes (Type I),<sup>ii</sup> and 1 in 1,000 children are born with Down Syndrome.<sup>iii</sup>

#### Estimated New Cases in the United States each year



*THERE IS NO SAFE AMOUNT OF ALCOHOL USE, AND NO SAFE TIME TO DRINK DURING ANY PART OF PREGNANCY.*



*Possible Physical Effects of FASD:*  
Brain Damage  
Facial Anomalies  
Growth Deficiencies  
Defects of the heart, kidneys, liver  
Vision and hearing problems  
Skeletal defects  
Dental abnormalities

*Of the population of individuals with FASD:*

*35% have alcohol and drug problems*

*35% of adults and adolescents had been in prison for a crime*

*45% engaged in inappropriate sexual behavior*

*60% of those over the age of 12 have been charged with or convicted of a crime*

*60% had disrupted school experiences*

*72% had experienced physical or sexual abuse, or domestic violence*

*82% are unable to live independently*

*94% also have a mental illness*

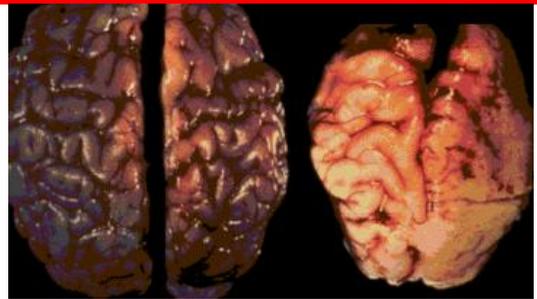
***100% of the cases were preventable.***

## HOW MUCH IS FASD COSTING US?

The cost to the nation of FAS, the least common and most severe of the disorders under the FASD umbrella, may be up to \$6 billion each year.<sup>iv</sup> The lifetime cost for an individual with FASD is about \$2 million.<sup>6</sup>

## WHAT CAN I DO TO HELP?

The statistics on the left are known as “secondary disabilities” that result from brain damage sustained due to alcohol exposure in the womb. Several protective factors can be provided to help people with FASD avoid these secondary disabilities such as: **early diagnosis, eligibility for disability services, a stable home, and a life free of violence.** It is important to remember that FASD is a lifelong condition with effects that differ from age to age throughout the lifespan. **These effects cannot be changed, but they can be accommodated.** Individuals with FASD can grow, improve, and learn to function well in life with proper support and services and accommodations. By catching the problem early, we can set up individuals with FASD for success, not failure, and make sure that they don’t fall through the cracks in the system. Because there is no cure for FASD (the damage is permanent) the need for accommodations may continue throughout an individual’s life. Help prevent FASD by spreading the word about the dangers of mixing alcohol and pregnancy, and help advocate for increased social services for those with FASD.



Compare these two infant brains. The baby on the left had no pre-natal exposure to alcohol, while the baby on the right’s mother drank throughout the pregnancy. Because the brain and central nervous system are developing throughout the entire pregnancy, alcohol can adversely affect the fetus at any time, causing “hidden” birth defects.

## FOR MORE INFORMATION ON FASD

- The National Organization on Fetal Alcohol Syndrome, <http://www.nofas.org>
- The FASD Center for Excellence, <http://www.fascenter.samhsa.gov>
- CDC, <http://www.cdc.gov/ncbddd/fasd/index.html>
- The Texas Office for the Prevention of Developmental Disabilities, <http://www.topdd.state.tx.us/>

### References:

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- <sup>2</sup> The Many Faces of Diabetes in American Youth: Type 1 and Type 2 Diabetes in Five Race and Ethnic Populations. The Search for Diabetes in Youth Study. *Diabetes Care* March 2009; Volume 32, Supplement 2.
- <sup>3</sup> May, P.A., and Gossage, J.P. 2001. *Estimating the prevalence of fetal alcohol syndrome: A summary.* *Alcohol Research & Health* 25:159-167.
- <sup>4</sup> [CDC. Prevalence of autism spectrum disorders---Autism and Developmental Disabilities Monitoring Network, six sites, United States, 2000. In: Surveillance Summaries, February 9, 2007. MMWR 2007;56\(No. SS-1\):1--11.](http://www.cdc.gov/mmwr/preview/mmwrhtml/ss0201a.htm)
- <sup>5</sup> Prevalence of Down Syndrome Among Children and Adolescents in 10 Regions of the United States. *Pediatrics* December 2009 (124:6):1565-1571.
- <sup>6</sup> Lupton, C; Burd, L; and Harwood, R. 2004. Cost of fetal alcohol spectrum disorders. *American Journal of Medical Genetics* 127C (671):42-50.
- <sup>7</sup> Burd, L.; Martsof, J.T.; and Juelson, T. 2004. Fetal alcohol spectrum disorder in the corrections system: Potential screening strategies. *Journal of FAS International* 2:e1.

## Appendix C

### ADVISORY STRUCTURE

TOPDD convenes leaders from across the state and across many disciplines and fields of expertise to address the prevention of developmental disabilities through two collaborative groups, the Texas FASD Collaborative and the Child Safety and Injury Prevention Task Force.

#### *Texas FASD Collaborative:*

The FASD Collaborative meets as a whole, and organizes subcommittees to work on specific issues. These issues include Screening and Brief Intervention to prevent FASD, building FASD prevention strategies into existing services for women using substance dependency and recovery programs, and Community & Professional Education. A Steering Committee leads the FASD Collaborative by coordinating the works between each committee.

#### *Child Safety and Injury Prevention Task Force:*

The Child Safety and Injury Prevention Task Force convene leaders that are active in various aspects of safety, including bicycle safety, early childhood issues, etc. The Committee oversees the Safety Awards program, and brings together diverse leaders to share best-practices on child safety.

#### *Advisory Members*

<b>Name</b>	<b>Agency</b>
Almeida, Connie Ph.D.	Fort Bend County Behavioral Health
Austin, Kay	Santa Maria Hostel
Ayala, Milton	Department of Family & Protective Services, Substance Abuse Programs
Beattie, Terry	Health & Human Services Commission, Office of Health Coordination and Consumer Services
Bellinger, Kelly	San Antonio Healthy Start, City of San Antonio Metropolitan Health Dept.
Benjumea, Melinda	MHMRA
Berry, Mary	Alpha Home Inc.
Betts, Esther	Behavioral Health Prevention, Mental Health & Substance Abuse Services, Department of State Health Service
Billings, Adrian M.D. Ph.D.	Pearce Clinic & Big Bend Regional Medical Center
Buckley, Kathleen N.P.	South Texas Alamo Chapter of the National Association of Pediatric Nurse Practitioners
Chaubal, Anjolie	Dept. of Family & Protective Services, Prevention & Early Intervention Division
Clements, Irene	Texas Foster Family Association
Cockerham, Cathy	Texas Court Appointed Special Advocates (CASA)
Cooper, Sam III LMSW-IPR	Department of State Health Services
Cortez, Debby R.N.	Texas Nurses Association
Crane, Barbara LSW	University of Texas Health Science Center
Craven, Susan	Texas Association for Infant Mental Health (TAIMH)
Crockett, Sarah	Texas Association for Infant Mental Health (TAIMH)

Crowell, Becca LCDC, LPC	Nexus Recovery Center, Inc
Dayal, Fran	Early Childhood Intervention, Department of Assistive & Rehabilitative Services
Draker, Sheryl J.D.	WJF Institute
Evans, David	Austin Travis County Integral Care
Galindo, Sandra	Department of Family & Protective Services, Specialty Nursing
Giardino, Angelo M.D., Ph.D.	Texas Children's Health Plan
Gil, Angela	WIC program, Department of State Health Services
Givens, Ashley	Texas Scottish Rite Hospital
Glenn, Ernie Judge	Bexar County Felony Drug Court
Hellums, Bonnie Judge	247th District Court, Harris County Infant and Toddler Court
Homan, Susan M.D.	Child, Family, & Adult Consultants
Hurley, Carole J.D.	Health & Human Services Commission
Jenkins, Laura	Fort Bend Council on Alcohol and Drugs
Kagey, Linda	Linda Kagey Counseling Services
Kiper, Valerie RM. MSN, NEA-BC	Universal Health Services, Inc.
Koslan-Joiner, Shelley	JPS Health Network
Kramer, Kathy Ph.D.	Office of Early Childhood Coordination, Raising Texas
Lane, Melanie	San Antonio Council on Alcohol and Drug Abuse
Lindsey, Michael Ph.D., J.D.	Southern Methodist University
McCarty, Laura	Harris County STAR Drug Court
McDonald, Holly	Council on Alcohol and Drug Abuse, Houston
Miles, Robert LCDC, AAC, ADC III	Texas Association of Addiction Professionals
Mitchell, Diana	Alpha Home Inc.
Mohrle, Charles	Rotary Club-Dallas
Moore, Gloria	Community Advocate
Petrilli, Kimberly MSPH, MSW	March of Dimes Texas
Pope, Ronald Judge	328th District Court
Quintero, Maria Ph.D	MHMRA
Quintero, Sonia	Communications Axes Ability Group-CAAG of South Texas
Ramirez, Lisa	Department of State Health Services, Women's Substance Abuse Services
Roberson, Jerry Ph.D.	United Associates
Roberts Scott, Joan	Department of Aging & Disability Services
Stewart, Kerby M.D.	Department of State Health Services, Substance Abuse Services Unit
Tijerina, Mary Ph.D	Texas State University School of Social Work
Tran, Nhung M.D.	Scott & White Healthcare
West, Emily MSW	University of Texas, Dallas
Wilson, Kim	Department of State Health Services, Child Health
Wind, Dori J.D.	Harris County District Attorney's Office
Wisdom-Wild, Julie	Alpha Home Inc.

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